Privacy and Security Solutions for Interoperable Health Information Exchange – Kansas

HISPC State Implementation Project Summary and Impact Analysis

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Submitted by:
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Submitted to:

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Executive Summary

This is the Final Report for the second round of funding – the State Implementation Project – of the Kansas Health Information Security and Privacy Collaboration. The first round ended in May 2007, with completion of the Final Reports of the Kansas Solutions Work Group and the Kansas Implementation Planning Work Group. That month, Kansas and other first round HISPC participants were invited to focus their next six months' efforts on achieving short-term outcomes for a subset of strategies in their Implementation Plans, while building additional momentum for their long-term objectives.

Kansas stakeholders reported their experiences in HISPCas positive – despite some mid-project frustration over perceived changes in methodology. The project's overall influence on Kansas' readiness to implement private and secure health information exchange was seen as constructive. For this reason, the Kansas HISPC Steering Committee chose three implementation strategies on which to focus in the second half of 2007:

- Establish a statewide coordinating entity to facilitate HIE and continue the work of the HISPC team.
- Coordinate the interpretation of state and federal laws pertaining to the exchange of health information in Kansas.
- Educate healthcare entities and the public about the benefits and processes of health information exchange.

These ambitious plans touched many areas of the public and private sectors and were adjusted somewhat during that process. Nevertheless, HISPC-II stakeholders made enormous strides toward fulfillment of these long term goals.

A proposal for a statewide HIE coordinating entity was delivered to the Governor by her HIE Commission in September. The Commission, its leadership, HISPC and the HISPC Steering Committee share many members in common, so the Steering Committee enthusiastically awaits the Governor's decision on the HIEC proposal.

Kansas HISPC's analysis of state and federal laws – the result of an extraordinary level of volunteered professional effort – was enormously successful and may serve as a model for other states.

Typical of other HISPC states, Kansas wrestled with the problem of how to engage consumers' voices in the project. The implementation phase of the HISPC project in the second half of 2007 explicitly sought to prepare consumers to participate more fully in this process by developing a HIT/HIE privacy and security curriculum for them. We believe that the involvement of hospital- and university-based Area Health Education Centers (AHECs) in developing and delivering the consumer curriculum prepares us well to complete our consumer-based work and go on to develop curricula for providers and other constituencies in future months.

The direct impact of this project – measured in statewide privacy and security outcomes rather than in project outputs – is somewhat more difficult to gauge. The health information technology landscape, as well as the privacy and security landscape, has changed primarily in response to outside forces. We note that what *has* changed due to HISPC is an expectation for

further change – in technology, in business policies and practices, and in laws and regulations. Clearly, though, this trend has not yet reached its "tipping point."

The most conspicuous outcome of the HISPC project in Kansas has been the engagement of a broad cross-section of stakeholders and policy makers in a discussion of privacy and security issues and statutory and regulatory reform. This project, as much as any of the state's HIT and HIE initiatives, raised the public's awareness of HIT/HIE and focused attention on the rights and responsibilities of those who share protected health information.

HISPC's direct impact on variation in business policies and practices in Kansas has yet to be realized; however, for us, these changes were not expected to happen in the short term. It is anticipated that through the HISPC assessment process and short term intervention strategies, the policies and practices will eventually be amended to facilitate the successful exchange of health information. The value of HISPC is in laying the ground work for this change to happen.

Many of the staff and leadership of the Kansas HISPC project believe that one of the most valuable benefits of the project has been the opportunity to meet with and learn from our counterparts in other parts of the country. HISPC-II enabled us to form multi-state collaborations to gain further leverage for our efforts in harmonizing state laws and educating consumers. These collaborations will enable Kansas to develop more effective policy and institutions at the local, regional and national levels. We are particularly pleased to be joined at this stage by our neighbors from Missouri, whom we actively recruited to the HISPC project. With our fellow states, we have developed funding proposals to carry these activities through 2008 and possibly beyond.

I. Introduction and Overview

I.a. HIT/HIE landscape prior to HISPC

At the start of 2006, Kansas was at an early stage of developing its health information exchange capabilities, but the state had a strong track record of public engagement in this process. In November 2004, Governor Kathleen Sebelius established the Governor's Commission on Health Care Cost Containment. (H4C). This Commission, under the leadership of Lieutenant Governor John Moore, was charged with recommending solutions to improve patient care and reduce costs by reducing duplicative and inefficient administrative processes and developing strategies for efficient and effective uses of health information.

Developing a statewide, shared vision for HIT/HIE was seen by the H4C as the next step in achieving interoperability and the mobilization of information to support patient care across the state. To pursue development of this shared vision or HIE roadmap, the Commission launched the Kansas Health Information Technology State Policy Initiative. A first step in the initiative was to survey health care stakeholders. Twenty-three Kansas healthcare industry leaders, including representatives from government, hospitals, physicians groups, health plans, employers, academic medical centers and advocacy groups were interviewed about the current status of HIT implementation and HIE in Kansas, HIT's potential to address the state's most pressing healthcare challenges and actions needed to move the state toward broader adoption and use of health information technology and exchange. These interviews confirmed that HIT and HIE were increasingly viewed as important tools to address the healthcare challenges facing the state.

Interviewees supported the development of independent regional health information networks that are coordinated and connected across Kansas. Most recommended the State serve as a coordinating body; providing leadership, guidance, and facilitation of a multi-stakeholder public/private collaborative effort to establish a statewide HIE roadmap. Barriers to statewide HIE identified by interviewees included: lack of interoperability standards, financing, and lack of stakeholder knowledge of HIT and privacy and security issues that impact the adoption and implementation of health information exchange.

The HISPC project aligned perfectly with the intent and direction currently underway in Kansas, and the work dovetailed with ongoing initiatives as well as planned activities. Critical to achieving interoperability in Kansas was an assessment of variations in organization-level business practices, policies and state laws related to privacy and security that posed challenges to health information exchange and the development of practical solutions to address these variations.

In 2005, the Governor's Health Care Cost Containment Commission retained the services of the eHealth Initiative Foundation to: a) increase awareness of HIT and HIE initiatives already underway in Kansas; b) catalyze and support those efforts; c) identify HIT/HIE adoption strategies and barriers to those strategies; d) bring Kansas' experience into the national policy dialog; and, e) build a broad Kansas coalition to improve the quality, safety and efficiency of healthcare through HIT and HIE.

An environmental scan conducted at the beginning of the Kansas Health Information Technology State Policy Initiative provided a look at then current HIT/HIE activities in Kansas. These activities, listed below, were described in the "Kansas Health Information Exchange Roadmap," a briefing paper written in partnership with the eHealth Initiative Foundation (eHI).[1]

- ***Central Plains Regional Health Care Foundation – Clinics Patient Index.*** The Clinics Patient Index is a shared repository of patient information that links six community clinics in Sedgwick County via a computerized patient enrollment and tracking system (a master patient index) through a secure website.
- ***Community Health Center (Health Choice) Project.*** Health Choice Network is an organization created by Community Health Centers for the purpose of delegating essential business services that can be more efficiently or effectively operated jointly. The result is that the Centers can serve more patients, offer more services, and enhance the level of care they provide to improve health outcomes.
- ***Jayhawk Point of Care (POC).*** The Jayhawk POC is an integrated solution that ties together all of the Pratt Regional Medical Center's key departments in a single database to improve the availability and communication of vital patient information. The Jayhawk POC will be expanded to reach all referral counties, providing a seamless point of entry for patients regardless of where they enter the system - the clinic level, the emergency level, the regional hospital level or the tertiary hospital level.
- ***Kansas City Health Exchange (KCHE) Community Health Record.*** Comprised of approximately 20 of Kansas City's leading employers and health care organizations, the KCHE developed a business plan for a Regional Health Information Exchange that would govern and manage a Community Health Record for the bi-state metro-KC area. The CHR solution developed for the KCHE consists of a central data repository that stores comprehensive, person-centric health data by aggregating information from health plans, pharmacy benefit managers, laboratories, and immunization registry data. Cerner Corporation, headquartered in the Kansas City area, was a key participant in this effort. The Kansas City Health Exchange became Healthe Mid-America and is now called CareEntrust.
- ***Northwest Kansas Health Alliance.*** The Northwest Kansas Health Alliance is the largest formal Critical Access Hospital network in the United States. The Alliance has linked members through telemedicine services and expanded them beyond the traditional boundaries of teleradiology. This program is supported by Hays Medical Center and is one of the largest programs of its kind in the country.
- ***Kansas Public Health eXchange (PHIX).*** PHIX is a Kansas public health initiative that provides a secure web-based communication system designed for the rapid exchange of public health information between providers.
- ***KAN-ED.*** This statewide initiative was established by the Kansas state legislature in 2001. Its objective is to bring broadband capabilities to hospitals and other member institutions within the state.

[1] Kansas Health Information Exchange Roadmap Briefing Paper, eHealth Initiatve, January 2006

- ***University of Kansas Medical Center, Center for Telemedicine & Telehealth.*** For fifteen years, the Kansas University Medical Center's nationally-respected Center for Telemedicine & Telehealth (KUCTT) has pioneered telehealth services to underserved Kansans throughout the state, making it one of the earliest and most successful telemedicine programs in the world. The KUCTT needed to facilitate the electronic data exchange and interoperability between 66 facilities, and has evolved into a network now utilized by over 30 different clinical specialty areas. It may be one of Kansas' "Best Practice" models. The program's success was highlighted in 1998, when KUCTT was given the American Telemedicine Association's (ATA) President award for the it's historical contribution to the field of telemedicine.
- ***University of Kansas Center for Healthcare Informatics (CHI).*** Nationally recognized, the KU-CHI is driven by the Institute of Medicine model to advance the utilization of health care information technology by empowering faculty and students with emerging IT toolsets. Most notably, the Simulated E-health Delivery System (SEEDS) project is a collaborative initiative developed to teach nursing and medical school students about HIT and electronic health records.

The Kansas Hospital Association, in a set of activities and interests parallel to those of the Governor's Health Care Cost Containment Commission, hosted in 2005 a number of well-attended statewide meetings as well as several subcommittee meetings of a body that came to be called the Electronic Health Record Work Group. This Work Group coordinated its efforts with the H4C and ultimately meshed their goals and activities for HIT/HIE with the Commission.

Also in 2005, the Kansas Department of Health and Environment (KDHE) was awarded an Information Links grant from the Robert Wood Johnson Foundation to work with the Kansas Health Institute, local health departments, KU CHI, Cerner Corporation, and others to:

a. research national best practices in electronically linking public health records with health information exchanges;

b. convene a steering committee composed of local health departments, foundations and associations to develop information sharing strategies and to overcome barriers; and

c. identify legal, administrative and jurisdictional barriers that present obstacles to the electronic sharing of public health information, and use this information to provide guidance to KDHE in creating an electronic linkage between the public health immunization registry in Kansas and the Kansas City Health Information Exchange.

Additionally, the Kansas Foundation for Medical Care in 2005 surveyed 522 primary care physician practices across the state, requesting information concerning their use of electronic clinical information. Twenty-one percent of respondents reported using electronic clinical information of some sort, and 81% reported that they use electronic practice management systems for administrative data. Of those respondents who did not currently use electronic clinical information, 32% were planning to move toward using electronic clinical information within twelve months.

Based on the urgency of the national agenda, activities underway in Kansas and progress made in other locales, there existed in 2006 a strong foundation for making significant progress in health information technology and health information exchange in Kansas. The Governor's Health Care Cost Containment Commission and the Kansas Health Information Technology Statewide

Policy Initiative were poised to address HIT/HIE privacy and security issues and develop and implement solutions that would remove barriers to interoperable HIE. Leadership and vision were driving these issues at the highest levels, and the opportunity to more closely examine challenges and barriers around interoperability, privacy and security were central to Kansas' then current HIE/HIT plan.

I.b. Current HIT/HIE landscape within the state

Because of the focus on HIT/HIE and in response to one of the primary recommendations of the Kansas HIT/HIE Statewide Policy Initiative, the Governor created by Executive Order the Kansas Health Information Exchange Commission (HIEC). To Chair the Commission, she appointed two members of the Policy Initiative who also served on the HISPC Steering Committee.

The HIEC was charged with furthering the recommendations from the Statewide Policy Initiative. As a result, HIT/HIE policy discussions have continued to have a high profile in Kansas. However, the private and public sectors have for the most part made only sporadic and uncoordinated attempts at HIT and HIE implementation. Anecdotal evidence and unscientific surveys suggest that the pace of HIT adoption and the rate of success in Kansas parallels that of the United States as a whole. To facilitate more rapid adoption, the HIEC in September 2007 submitted a recommendation to the Governor for creation of a public/private HIE Coordinating Entity.

Ongoing HIT/HIE organizations and initiatives in Kansas not reported in the 2005 environmental scan include:

- ***Kansas University Medical Center*** and a number of other hospitals throughout the state have installed new electronic medical records systems. Many other health care systems in Kansas continue to adopt clinical information systems to support HIT/HIE environments.
- ***Browsersoft, Inc.*** Developers of the OpenHRE open source software toolkit for standard and secure data exchange between existing health records systems, Browsersoft was a member of a consortium that successfully built and demonstrated a prototype for the Nationwide Health Information Network in 2006.
- ***KC Carelink.*** Established in 2001, KC CareLink is a collaborative project of Kansas City healthcare safety-net providers. Together they have developed a shared electronic information network. Participating organizations use a web browser to connect to a central database, where they can access KC CareLink applications to share a uniform set of individual patient information for the purpose of creating referrals and establishing a "medical home".
- ***The Outcomes/Information Sharing/Information Systems Committee of the Mid-America Regional Council Regional Health Care Initiative.*** The project is working with safety net clinics and other stakeholders in metropolitan Kansas City to develop projects and initiatives that allow the safety net community to work more closely together. A critical element of this initiative involves the sharing of information and the information technology systems that support such sharing. This includes assessing and enhancing the information systems of individual clinics, enhancing the capacity of safety

net clinics and stakeholders to communicate and coordinate with each other and their clients, working with KC CareLink and other stakeholders to develop a regional information sharing system, and monitoring and participating in regional, state, and national initiatives to enhance health care information systems.

- ***The Kansas City Regional Electronic Exchange (KCREE).*** A collaboration of St. Luke's Health System in Kansas City, Commerce Bank, and Blue Cross Blue Shield of Kansas City, KCREE is a pilot information exchange solution. KCREE serves as a clearing house that shuttles information directly between payers and providers.
- ***The Kansas City Quality Improvement Consortium.*** KCQIC was formed by the United Auto Workers – Ford Community Health Care Initiative and community stakeholders to address health care quality in the greater Kansas City area. In February 2007, the Robert Wood Johnson Foundation's "*Aligning Forces for Quality, The Regional Market*" project awarded KCQIC a Community-Based Initiative grant designed to help improve the quality of health care provided to people with chronic illnesses.
- ***Sedgwick County CHR.*** A Community Health Record pilot project was implemented in 2006 for the Medicaid managed care population in Sedgwick County to improve quality, safety and cost-effectiveness of care. The project was initiated in partnership with Cerner Corporation and FirstGuard Health Plan, and had many elements in common with an earlier partnership between Cerner and the State of Tennessee. The CHR allows authorized providers online access to aggregated claims data and health transactions regarding a person's office visits, hospitalizations, medications, immunizations and lead screening data. The success of the project has led to a proposal to expand the CHR throughout the state.

I.c. Privacy and Security landscape prior to HISPC

The privacy and security landscape in Kansas prior to the HISPC project was summarized in the March 2007 HISPC Solutions report. The critical observations and key issues identified there were:

Patient focus:

- Establishing patient consent. Clarifying and coordinating patient consent and authorization for data uses and disclosures is a paramount concern. A related issue is how to adequately prepare patients to make informed decisions about the disposition of their clinical data.

Business operations focus:

- Electronicization. The vast majority of health care providers in Kansas have not yet adopted electronic information technologies to manage and store clinical data. Current information safeguards, therefore, are overwhelmingly manual. Adaptation of existing policies and procedures to an interoperable electronic environment presents a significant challenge.
- Weak policies. Health information exchange security in many places is governed by workgroup behavior norms rather than adherence to formal policies and procedures, even where formal policies and procedures do exist. Though behaviors and policies often coincide, in some cases behavioral norms circumvent policies.

- Narrow policies. Many providers process protected health information in non-clinical applications such as billing systems. Formal polices and procedures for protecting information privacy and security are common in such venues. However, these policies and procedures focus mainly on internal business operations and largely do not address information exchanges with outside parties, except for claims submissions for payment.

Legal focus:

- Weak understanding of the law. Most businesses diligently attempt to comply with Kansas law and with their particular interpretations of HIPAA. But state privacy and confidentiality laws are fragmented and are weakly understood. Interpretations of the law vary greatly, so the quality of implementation may be inconsistent and "HIPAA compliance" is sometimes used as a pretext for unnecessarily complicating or denying requests for HIE.
- Antiquated state laws. Kansas statutes and administrative regulations are antiquated and largely failed to contemplate electronic health information exchange. Stakeholders seem to be unaware of or unconcerned with the potential legal pitfalls resulting from the interplay between state law and administrative regulation and HIPAA requirements, even though they are keenly aware of the need to honor patient privacy. They may use "HIPAA" as the rubric for any and all restrictions on HIE to maintain patient privacy.

Regional focus:

- Multi-state solutions. Much health information exchange in eastern Kansas is interstate; therefore business and legal solutions must be coordinated regionally.

The Kansas HISPC Solutions Work Group (SWG) found virtually no *current* business policies and practices that inhibit health information exchange because those business policies are too onerous. Most business policies and practices for exchange of health information in Kansas were written to apply to paper records. In practice, these have been supplanted by the expedients of workgroup behavior norms that keep work flowing with or without strict compliance to business policy. To the extent that it exists in this area, structure has been liberating.

This point of view may be contrasted with often-heard complaints about HIPAA in Kansas and at the national level. In the 18 scenarios considered by the SWG, HIPAA-compliance was often cited as a process constraint, but it was seen as a mechanism that channels activity rather than inhibits it. Though individual interpretations of HIPAA vary widely, there is little confusion about the distinctions drawn between §164.506 (Treatment, Payment or Health Care Operations) and §164.508 (Uses and Disclosures for which Authorization is Required, *e.g.* marketing.) The cost of compliance (*e.g.*, keeping records of uses and disclosures) seems to have been absorbed, albeit unenthusiastically, without inhibiting critical information flows under most circumstances.

The Kansas SWG did hear some concerns that *future* business policies and practices thought to be associated with electronic health information exchange might inhibit *adoption* of electronic HIE. In the debate among health care providers, suppliers and insurers over the business case for adoption of electronic health records, the dominant themes are: unproven benefits, total cost of ownership, and work flow disruption.

Prospective adopters of electronic HIE expressed discomfort with technology that requires wholesale modification of their customary business practices in order to keep it working or to

keep it from failing its business purpose or its security promise. This issue is exacerbated by the often-repeated concern that significant investments may be wasted if new systems become outmoded because of changes in government requirements or in technology. The SWG report suggested, however, that it may be a mistake to evaluate transformational technology using incremental change criteria. A new generation of professionals with few entrenched habits has the capability to invent new business models that exploit the best features of the old and the new methods.

Privacy and security concerns center on fears of loss of control: 1) the inability of caregivers to access the information they need when they need it; 2) the disinclination to make clinical decisions solely on the basis of the received electronic record; and conversely, 3) the inability to prevent unauthorized access by outsiders into electronic information systems. Thus, they fall mostly within the work flow discussion.

The first concern – inappropriately denied access – has been somewhat mitigated by lessons learned in the aftermath of the Hurricane Katrina disaster. The electronic medical records of 50,000 patients of the VA Medical Center and surrounding veterans' outpatient clinics survived the flood and were fully available four days later, using computers in Houston.

The second concern – undependability of records – may only be resolved after interoperable electronic systems have established a proven track record. The third concern – unauthorized access – is more nettlesome. Most end-users of technology do not understand the inner workings of that technology. They may rely on anecdotal evidence to evaluate privacy and security claims made for new information systems. However, objective research on the vulnerability of electronic medical record systems has begun to emerge, and the results are disquieting, as we shall see below.

I.d. Current Privacy and Security Landscape

The privacy and security landscape in Kansas – involving current statutes, regulations and business practices – is essentially unchanged in the 18 months since the start of the HISPC project. What *has* changed is an expectation for change. Though this expectation clearly has not yet reached its "tipping point," we are witnessing a growing number of privacy and security policy decisions that are reaching the attention and interest of the general public as well as their elected representatives. Providers and consumers are more aware of the need and the strategies for change in order to secure the future of HIT/HIE.

The change in expectations undoubtedly began with the 2003 HIPAA Privacy Rule compliance deadline. Since then, turbulent (because they rarely progress in a straight line) forces of technology and politics have begun to align and accelerate towards a clearer set of opportunities and needs. Most recently:

- In October 2007, Donald Kerr, Principal Deputy Director of National Intelligence argued for a redefinition of "privacy." During a discussion of the Foreign Intelligence Surveillance Act, he said, "Protecting anonymity isn't a fight that can be won. Anyone that's typed in their name on Google understands that."

- In October 2007, Microsoft Corporation announced a new free service called "HealthVault," offering Internet-accessible personal health records. Within days, Google promised an online health platform including personal health records that would be available in 2008.
- In 2006 and 2007, Kansas Senator Sam Brownback and Kansas Representative Dennis Moore introduced legislation to create Independent Health Record Trusts that explicitly grants ownership to patients of their electronic health records stored in health record banks.
- In 2007, the Centers for Medicare and Medicaid Services awarded numerous Medicaid Transformation Grants to states developing electronic health records or health record banks for Medicaid beneficiaries.
- In October 2007, the Kansas Health Policy Authority identified 21 health reform options for the coming year. Among these was a proposal to implement a statewide community health record for beneficiaries of Medicaid, SCHIP and the State Employees Health Plan.
- Every health insurance reform proposal put forward by a presidential candidate in 2007 has had a health information policy component.
- In 2005, the State of Kansas was awarded an InformationLinks grant by the Robert Wood Johnson Foundation to identify legal, administrative, and jurisdictional barriers that present obstacles to the electronic sharing of public health information. This information provided guidance for creating an electronic linkage between the public health immunization registry and a private employer-based health information repository.
- In September 2007, an independent research organization reported the disquieting findings of their 15 month study of EHR system vulnerabilities. The eHealth Vulnerability Reporting Program (eHVRP), a collaborative of health care industry organizations, technology companies and security professionals, found that currently available commercial EHR systems were as vulnerable to exploitation as any other complex applications. The recommendations of the eHVRP were consistent with Kansas' aims for HISPC implementation. Among their recommendations were:
  - better collaboration between customers, EHR vendors and information security vendors to facilitate exchange of vulnerability information;
  - creation of educational material and support outreach on information security issues relating to ehealth systems;
- In October 2007, the Wall Street Journal and other national press ran a series of articles on medical identity theft.
- In September 2007, the Kansas Health Information Exchange Commission delivered its proposal to the Office of the Governor for creation of a public/private HIE Coordinating Entity. This proposal was an outgrowth of the Kansas HIT/HIE Policy Inititative – particularly, the work of its Governance Workgroup. The Workgroup spent considerable effort considering potential responsibilities, financial and non-financial resource requirements and governance structures for a coordinating entity. This recommendation for a governance structure was also sited in the HISPC implementation plan. As of November 2007, those recommendations are still under review.

- A related proposal from the Kansas Health Policy Authority (KHPA) envisions a "Health Information Technology/Health Information Exchange (HIT/HIE) Advisory Council" to provide ongoing feedback to the KHPA about the development and implementation of its statewide CHR, taking into account the work of the Governor's Health Care Cost Containment Commission, the Health Information Exchange Commission, and the Kansas Health Information Security and Privacy Collaboration (HISPC) project. The HIT/HIE Advisory Council could also provide guidance on the means to provide education and technical support for health care providers interested in integrating health information technology into their practices. Consumer and provider input to this process would be critical. This proposal clearly anticipates HISPC's future work with multi-state collaboratives to harmonize laws and to educate and reach out to the public.

II. Implementation Project Update

II.a. Reasons for choosing implementation projects

Kansas stakeholders identified hundreds of variations in business practices that were seen as potential impediments to the adoption of health information technology. These tactical issues were reorganized by the Solutions Work Group into four strategic areas: patients, business operations, legal issues and regional issues. We believe that successful solutions will be those that gain consumer acceptance and create market demand for new information products and services. We intend to encourage Kansas stakeholders to continue to invent modest local and regional "pilot" solutions. By empowering these pilot solutions and initiatives, we hope to better understand their feasibility, share lessons learned and extend their successes.

The process of vetting, evaluating and prioritizing solutions was related to Kansas' HISPC communication strategy, feasibility analysis and implementation planning. In Kansas, these strategies and processes were not designed primarily to determine the purely technical or financial feasibility of solutions, nor their current legality. Rather, Kansas' strategies were designed to determine the acceptability of various solutions to different stakeholders and to discover opportunities to forge consensus among potential participants in health information exchange.

Much of this work was coordinated with the Health Information Exchange Commission (HIEC), established in February 2007. The HISPC Implementation Planning Work Group report submitted in April 2007 identified six high-level implementation goals and strategies that were cross-mapped to the Solutions Work Group's four broad solution strategies and to the HIEC's mission. The six implementation goals were:

1. Establish a statewide coordinating entity to facilitate HIE and continue the work of the HISPC team
2. Coordinate the interpretation of state and federal laws pertaining to the exchange of health information in Kansas
3. Identify healthcare informatics standards and best practices to improve the exchange of health information and monitor the evolution of national platforms.
4. Develop model policies, procedures, and guidelines for the exchange of health information
5. Educate healthcare entities and the public about the benefits and processes of health information exchange
6. Promote implementation of health information exchange

The HISPC team recognized goals 1, 2 and 5 as most critical, because they would establish legal and organizational infrastructures from which Kansas could launch its remaining three strategies.

II.b. Progress made on the implementation plan to date.

II.b.1 Establish a statewide coordinating entity

At the time that Governor Sebelius established the Health Information Exchange Commission, in February 2007, Kansas' initial round of HISPC funding was within two months of completion. The purpose of the HIEC was, in part, to build upon, and to provide continuity for, the work of HISPC and the Governor's statewide HIT/HIE Policy Initiative. The HIEC mandate included a focus on health information security and privacy concerns as well as a broader focus on promoting widespread adoption of health information technologies. Several prominent members of the HISPC and Policy Initiative teams were appointed by the governor to serve on the Commission. When HISPC funding was renewed for the second half of 2007, the two entities continued on complementary and mutually supportive paths.

In late summer of 2007, the Governor's Office indicated its willingness to receive a proposal from the HIEC for establishment of a statewide coordinating HIE entity of the type that had been originally recommended by the HIT/HIE Policy Initiative and subsequently embraced by the HISPC Implementation Planning Work Group. The process and timeline for development of the proposal under the auspices of the HIEC were slightly different from those outline in the HISPC II proposal; however, it was necessary to move forward with the plan in order to be on target with the upcoming budget process. The HIEC proposal for the coordinating entity was reviewed by several HISPC steering committee members, who were largely in agreement on the outcome. This opportunity was considered likely to be the only one available for the remainder of the year.

In September 2007, the Governor's HIEC presented its recommendations to her Office. As of November 2007, those recommendations are still under review.

II.b.2 Coordinate the interpretation of state and federal privacy laws

The HISPC Legal Work Group (LWG) set for itself two goals for the second half of 2007:

1. Produce a catalog of existing statutes and regulations in Kansas that affect health information privacy and security, with implications for electronic exchange. Using this catalog, we will identify broad areas of Kansas statutes that could be harmonized with neighboring states' laws and with federal law. Analysis of the full catalog is planned for 2008. A "parking lot" strategy will be used to collect the cataloged statutes and regulations into fewer places, so that they can be modernized in a coordinated and consistent fashion. A future phase of the project also will attempt to address areas affecting health information exchange in which current state laws and regulations are silent.
2. Propose, for the Governor's consideration, general legislation for the 2008 state legislative session to facilitate the secure exchange of electronic health information while protecting health information privacy rights. The Kansas HISPC report noted that existing state law largely fails to contemplate electronic health information exchange, causing confusion among stakeholders and variations in business practices. New legislation will be designed to diminish these variations in business practices by

specifying base privacy and security standards. These could take the form of a default provision that ties Kansas laws to HIPAA.

These actions seek to mitigate the barriers that arise from citizens' uncertainty about the rights and responsibilities of all parties to HIE. We believe that clarifying the law will reduce perceptions of risk and will foster increased adoption of HIT/HIE. We also hope to educate lawmakers about the need to create safe harbors from enforcement of federal and state privacy and security laws. New laws are intended to be more transparent than those that they supersede, but safe harbors may help to reduce fears among potential HIT/HIE adopters that they may unintentionally violate existing laws.

By November 2007, the LWG had accomplished the following:

1. LWG staff identified broad topic areas under which Kansas law relevant to health information security and privacy would fall. These topic areas include:
    a. Public Health – Includes laws that regulate various health professions and entities as well as laws directed at overall public health, such as disease reporting.
    b. Insurance - Includes laws that result in information disclosure related to the processes of public (e.g. Medicaid) and private health insurance.
    c. Minors - Includes laws that may result in or relate to the disclosure of minors' information. Contexts that include the disclosure of minors' information may include treatment, custody proceedings, criminal proceedings, child-in-need of care, etc.
    d. Mentally Ill - Includes laws that result in or relate to the disclosure of health information of mentally incompetent persons or those being adjudicated as such.
    e. Domestic Relations - Includes laws that may result in disclosure of health information in the context of domestic proceedings (*e.g.*, divorce and child custody/residency hearings).
    f. Civil Procedure - Includes laws that may result in disclosure of information in civil court and administrative proceedings (e.g. court ordered physical/mental exams).
    g. Criminal Procedure - Includes laws found in the criminal code that may result in disclosure of information (*e.g.*, required reporting of gun shot wounds) and laws found in other codes that may pertain to criminal proceedings (*e.g.*, mandatory reporting of abuse).
    h. Law Enforcement - Law enforcement - Includes laws that result in disclosure of information related to law enforcement activities and inmates (*e.g.*, court ordered testing of communicable diseases after assaults).
    i. Other – Includes any laws identified that do not fit into one of the above categories.
2. Research parameters were established. Specifically, it was determined that the catalog should include:
    a. Laws that pertain to the collection, use, or disclosure of individual health information.
    b. Laws where individual health information is relevant to determining compliance or violation of a law.

3. To ensure consistency in data collection processes, a data collection tool was created using Microsoft Excel. The tool was designed to collect laws within the scope of the project, categorize them according to identified topics, and document the general applicability and purpose of the specific law identified. The tool was structured in the following format:
    a. A "Directions" sheet provided background information about the project, data collection parameters, and technical instructions for conducting the research and populating the tool.
    b. A "Resources" sheet provided links to agencies whose scope of authority potentially impacts the collection and exchange of health information
    c. Specific sheets for "Public Health," "Insurance," "Minors & Mentally Ill," "Domestic Relations and Civil Procedure,"" Criminal Procedure and Law Enforcement" and "Other" were created. Each sheet defined the topic(s) involved, re-stated research parameters, and provided "suggested" research authority (*e.g.*, relevant statutory chapters and agencies). For each law entered into a sheet the following information was provided:
        i. Citation (with hyperlink to online source for law, when possible)
        ii. Description of law
        iii. Setting/Profession regulated by law
        iv. General purpose of the law (*e.g.*, treatment, payment, public health, abuse/neglect, health oversight, civil proceedings, criminal proceedings, threat to health/safety, patient/personal rep access and "other.")
4. Eleven researchers were identified and assigned one or more specific topic areas to research. They were trained through live training sessions. Training topics included:
    a. Project background & purpose
    b. Research parameters
    c. Technical process for conducting research (e.g. Web based sources for current statutes and regulations) and populating the tool.
    d. Deadlines.
5. Researchers reported to designated LWG staff on a weekly basis and as needed for questions and clarification. As researchers completed portions of the tool, they provided those portions to their designated LWG staff who then merged the sections into a Master tool. LWG staff then conducted final formatting and standardization of the tool in terms of headings, font, etc., and conducted an initial gap analysis to assure that the appropriate bodies of law had been researched.
6. Through this process, the "Catalog of Laws" was completed by October 15th.
7. The data collection tool was revised for use by the LWG members. Specifically, the Directions page was revised and a sheet labeled "Analysis" was added.
8. The revised tool was provided to members of the LWG for analysis. Responsibility for analysis was divided according to LWG members' respective areas of expertise.

9. As the proposal for HISPC III was being developed there was a much discussion among the Collaborative members regarding terminology, definitions, and development of a consistent understanding of the tasks involved in the process of collecting and assessing statutes which involved medical privacy issues. Kansas was able to contribute significantly to this dialogue, having developed and compiled a systematic method for collecting and analyzing the statutes during this period. This process greatly benefited the Kansas efforts as the collaborative discussion considered questions and issues which were then compared with the Kansas assessment tool in the process of evaluating the method, and use of the assessment tool.
10. During the drafting the LG WG Collaborative Proposal, Kansas contributed ideas and content for the opening section, assisted with development of the project management plan, and drafted the content for additional considerations.

For the remainder of the year, the LWG plans to accomplish the following:

11. From their review of assigned areas, the LWG will identify laws in the tool that specifically relate to the privacy of individually identifiable health information. This means the law must:
    a. Have the specific purpose of protecting the privacy of health information; or
    b. Affects the privacy of health information in a direct, clear, and substantial way.
12. As LWG members identify laws from the tool that specifically relate to the privacy of individually identifiable health information, they will copy and paste those laws into the analysis sheet. The Analysis sheet is designed to refine the catalog of laws and facilitate the development of proposed legislation by:
    a. Repeating the "Citation," "Description," and "Setting/Profession Regulated" information (the portion copied & pasted)
    b. Adding a "Covered Entity" box to identify whether the "Setting/Profession Regulated" will potentially sweep in HIPAA covered entities.
    c. Adding a section for analyzing "State Law's Relationship With HIPAA Privacy Rule." This section is designed to facilitate a preemption analysis between the Privacy Rule and the identified state law
    d. Adding a section for commenting on the State Law's fitness for Health Information Exchange
    e. Adding a section for commenting on the State Law's relationship/consistency with other federal and state laws
13. Information derived from the refinement process and analysis will be used in modeling template legislation for submission to the Governor by December 31, 2007.

II.b.3 Educate the public

The HISPC team envisioned that the first project to be undertaken by the newly established statewide coordinating entity could be the development of a resource center which would include development of a toolkit (*e.g.* curriculum outlines, teaching strategies, outreach plans, etc.) for educating Kansans about electronic exchange of health information. The curriculum would focus on privacy and security issues and the state and federal laws governing the exchange of HIE. This tool kit would be designed to address the needs and concerns of policy makers, consumers and health providers.

The need for consumer education related to HIT/HIE initially became evident as Kansas worked through the identification of variations in business practices and policies related to the electronic exchange of health information. It became a major recommendation in the HISPC Solutions and Implementation plans. It also was identified in the Kansas HIT/HIE Policy Initiative.

Consumers need to have knowledge and information about HIT/HIE if they are to make informed decision about there health care. A central issue to the ubiquitous use of health information technology as well as a sustainable business model for health information exchange is education, engagement and trust of consumers. HISPC II provided a unique opportunity for us to focus on consumer education. To address the issue a consumer education work group (EWG) consisting of key stakeholders throughout the state and the bi-state Kansas City Area was organized to: 1) analyze market characteristics and select a segment of the market to target in Kansas; 2) develop curriculum content and teaching strategies; and 3) produce instructional materials.

By November 2007, the EWG had accomplished the following:

1. Based upon the existing state of HIT/HIE in Kansas, the consumer education work group decided to focus our education on rural consumers. Kansas is primarily a rural state, with 100 out of 105 counties categorized as rural. In Kansas, 107 out of 138 hospitals are located in rural areas. As the adoption of HIT in Kansas continues to expand, there is a growing concern about adoption in the rural communities for a variety of reasons. With this in mind, it seemed appropriate to target education to this particular market segment.
2. The work group discussed consumer education and developed a content outline that initially focuses on the following content areas:
    a. Overview of the National Health Information Network and national HIT/HIE initiatives;
    b. Overview of state and regional initiatives related to HIT/HIE;
    c. Relevant legislation and legislative issues;
    d. Explanation of how data is used and exchanged (use cases);
    e. Rights, risks and opportunities of HIE;
    f. Personal health records;
    g. e-prescribing.
3. The work group recognized the need to examine existing consumer education materials and adapt those materials to meet the specific needs of the diverse rural consumer groups in the state. Through this education work group we learned that the state chapter of the

American Health Information Management Association (KHIMA) was in the process of launching a "train the trainer" campaign for consumer education related to "Your Personal Health Information: How to Access, Manage and Protect it". To date, approximately 60 trainers (in Kansas alone) have been trained on the content and delivery methods. We have discussed our plans with AHIMA representatives and have their permission to adapt and expand this foundational content giving credit to AHIMA where credit is due.

4. The work group suggested that we engage a diverse group of rural consumers in Kansas to determine their knowledge and attitudes regarding privacy and security issues related to HIE.
5. Producing educational materials in different languages and literacy levels was also suggested.
6. A variety of teaching strategies and modes of delivery were identified. The delivery modes will be determined by the targeted rural consumers.
7. Area Health Education Centers (AHECs) and consumer education networks in Kansas will assist with needs assessment and delivery modes.
8. It was determined that we would coordinate with the legal work group as they determine educational content related to legal issues and statutory changes related to HIE.
9. As this plan was unfolding, the leaders of the Education Work Group began to work with the HISPC multi-state Consumer Education and Engagement Collaborative to leverage each state's resources. Several of Kansas' suggestions are being incorporated into the Common Collaborative project as well as Kansas' individual state portion of the Collaborative.
10. The Consumer Education and Engagement Collaborative have met weekly to discuss plans and to design the proposals. Kansas has contributed to the core project by writing the section on tool development, content outline, teaching strategies and outcome measurements. The draft of the final proposal was submitted to RTI on November 16.

For the remainder of the year, the EWG plans to accomplish the following:

11. By December 31, we will:
    a. Review the AHIMA curriculum especially as it relates to the privacy and security issues surrounding personal health records and HIE and identify any gaps in content.
    b. Develop a plan to leverage the work of Kansas AHIMA as we begin to educate rural consumers.
    c. Begin development of a glossary of terms related to privacy and security to be used to educate rural consumers to be sure everyone is addressing the subject from the same reference point.
    d. Submit an individual state consumer education proposal in cooperation with the Consumer Education and Engagement Collaborative.
    e. Collaborate with AHIMA to leverage and expand their consumer education program.

II.c. Issues encountered during implementation. Lessons learned.

II.c.1 Legal Work Group

Kansas' approach compared to other select states.

1. Additional details about Kansas' approach
    a. The Kansas approach was framed around the two LWG deliverables of the HISPC project: i.) Proposing general legislation for the 2008 state legislative session to facilitate the secure exchange of electronic health information while protecting health information privacy rights; and ii.) Producing a catalog of existing statutes and regulations in Kansas the affect health information privacy and security, with implications for electronic exchange.
    b. To propose the general legislation that would be most useful to stakeholders, the Kansas LWG determined that the catalog of existing statutes and regulations needed to be developed prior to drafting legislation. By having a catalog first, the LWG members are provided with a "landscape" of Kansas law. That landscape is essential in tailoring legislation to meet specific Kansas needs.
    c. Kansas was particularly fortunate in obtaining the participation of a large number of attorneys from a broad array of private and public sector organizations, much of whose time was donated *pro bono*.
    d. The specific process for creating the Kansas catalog has been previously outlined. The overall structure of the tool (*e.g.*, using separate sheets for each topic) divided a vast amount of law in to manageable sections for research purposes. The tool also facilitated the categorization of that law into more specific topic areas (*e.g.*, treatment, payment, etc…), which will be useful as the analysis of Kansas law continues in the long term. The second deliverable – creating legislation – is a multi-faceted process. The tool supports one piece of that process. The "analysis sheet" specifically addresses the cataloged laws' relationship with the HIPAA privacy rule as well as other federal and state laws. The process of conducting the analysis assists in modeling legislation that is most useful to Kansas.
    e. Notably, in Kansas, no broad public survey of Kansas law pertaining to health information security and privacy occurred prior to the HISPC project. Therefore, the process for developing the catalog was not built upon any preexisting catalog or other projects. Further, Kansas has no existing HIE legislation to build upon.
2. Other select states[2]
    a. Florida –Florida developed draft HIE legislation first, then created a catalog of laws. The catalog of Florida laws is organized into broad categories based on setting as well as specific sub-categories such as those related to communicable disease and minors. Producing the legislation prior to the producing the catalog helped ensure that the laws most impacted by the legislation were included in the catalog. However,

[2] Based on information available on SharePoint

producing the legislation first may have an unintended effect on laws not identified through the prior development of a catalog.

b. Michigan – Michigan's catalog has a foundation in previous state sponsored activities, therefore the current Michigan catalog is quite refined. It is categorized by Purposes of HIE (purpose of disclosure), HIE Participant/Access (setting of disclosure), HIE Operations (technical requirements for security etc…), Liability Issues, Donated Technology, Discovery and Evidentiary Issues, Funding, and Definitions. The advantage of this approach is that it incorporates multiple dimensions of use and disclosure of health information that are applicable in an HIE environment. As discussed below, the Kansas model is similar to the Michigan model, but is at an earlier stage of development.

c. Comparison with Kansas –

   i. Approach: The approach for organizing the catalog of laws in Kansas is similar to both Florida and Michigan. The broad categorization of law used by Kansas is tied to the underlying purpose of a disclosure rather than the setting of disclosure. The narrowed categories of law used in the Kansas catalog serve to provide refined information about the specific purpose of an underlying disclosure (*e.g.*, the disclosure was for treatment or the disclosure was for judicial proceedings, etc.)

   This methodology for categorization of law was applied because it was consistent with the organization of the HIPAA Privacy Rule. The Privacy Rule does not organize disclosures by setting, but rather organizes disclosures by underlying purpose. The only reference to a specific type of record contained in the privacy rule involves provisions for the disclosure of psychotherapy notes. Since many of the stakeholders that disclose health information in Kansas are HIPAA covered entities, the LWG determined that structuring the catalog similar to HIPAA would be most useful.

   Further, categorization is a multi-step process. Since Kansas had no preexisting catalog of laws, the current Kansas catalog is still in the early stages of refinement. The catalog tool was designed to facilitate the later stages of refinement by including information about setting regulated, covered entity status, and specific purpose of disclosure. As the LWG activities continue in 2008, the catalog will be further refined.

   ii. Process: The Kansas process for legal research was driven by the legal research resources available. Search technology provided through paid subscription resources (*e.g.*, Westlaw and LexisNexis) provide the ability to easily conduct very refined queries of all categories of federal and state law. In absence of a paid subscription, research must be conducted through credible state-specific online resources. For example, links to current Kansas statutes and regulations are accessible through the Kansas Legislature web site. The site also permits "key word" searching of the statutes and regulations through a basic search engine. The structure of legislative/regulatory sites and search tools available in other states are not identical to Kansas. Therefore, the research process among the states will not always be identical.

II.c.2 Education Work Group

1. As we worked through the implementation, it became very clear that we needed to engage rural consumers in the process to target the consumer education to their specific needs and desires for delivery of the content. This became more evident as we worked with other states in the HISPC multi-state Collaborative and participated in the HISPC national meeting.
2. It also became evident that there are an abundance of educational materials that are available for consumer education. We need to evaluate and adapt these materials as appropriate and identify gaps in resources so new materials can be developed where gaps exist.
3. We learned that the Kansas Health Information Management Association (KHIMA) has developed a train the trainer program to educate consumers about Personal Health Records (PHR). This initiative is being rolled out across Kansas and will target some rural areas of the state as well as the urban and metropolitan areas. This organization has agreed to work with us on the privacy and security issues so that we can deliver consistent messages.
4. We learned that it was ambitious of us to state that we would " have a curriculum, teaching guide and evaluation plan" in place by December 31. What we will have is a content outline, a list of strategies and modalities for delivering the message and outcome metrics to assess success, along with a beginning glossary of terms related to privacy and security.
5. For six weeks, we spent a great deal of time working with the consumer education collaborative to develop a multi-state plan for consumer education and engagement which in the long term would help all states move forward with educating consumers about all phases of knowledge and engagement in HIE.

II.d. Plans for continuing the project

Kansas plans to continue the HISPC project through two collaboratives: 1) Harmonizing State Law; and 2) Consumer Education and Engagement.

II.d.1 Harmonizing State Law

Goals:

i) Complete a gap analysis in 2008, producing a draft plan for draft legislation by the 2009 session to harmonize state privacy and security laws with HIPAA.

ii) With the multi-state Collaborative, develop a tool kit and roadmap for application in other states.

Objectives:

i) Educate Kansas leadership and stakeholders about health information exchange and issues related to HIE privacy and security.

ii) Identify and remove statutory, regulatory and procedural barriers to interoperable HIE.

iii) Develop medical privacy legislative proposals which will enable the secure, interoperable exchange of health information including consideration of a possible mandate for statewide coordination of HIE.

iv) Through a collaborative process, gather and incorporate public comment on the proposed legislation.

v) Test and refine analysis tools including taxonomy, ranking method, tool kit and roadmap developed by the Collaborative.

Activities:

i) Development of taxonomy to facilitate analysis of state laws addressing health information.

ii) Development of basic model privacy law and legislative package which will enable recodification of statutes and drafting of new legislation to enable health information exchange

iii) Preparation of an inventory of existing materials in each HSPL State that identifies or analyzes the health privacy laws within that state

iv) Development of a template (the "Analysis Template") that provides a uniform means of analysis of state laws by general taxonomy or areas of law.

v) Based on work completed in Phases One through four, we will assist with development of recommendations for Collaborative HIE legislative package, toolkit and roadmap, to provide guidance to other states undertaking similar initiatives.

vi) Co-Lead Phase III with Florida

vii) Work closely with neighbor state, Missouri to align efforts.

Deliverables:

i) Inventory and gap analysis of current state medical privacy laws

ii) Narrative about experience with the toolkit developed as part of the collaborative

iii) Development of draft plan for legislative proposal and outreach.

iv) Recommendations on changes to the tools for future use

II.d.2 Consumer Education and Engagement Collaborative

Kansas is one of seven states (CO, KS, MA, NY, OR, WA, WV) working within the Consumer Education and Engagement Collaborative to continue our efforts to educate consumers with an emphasis on rural consumers as described above. We will participate in the core project as well as in the state specific project. The outcomes of our state specific project will contribute to the comprehensive tool kit being developed by the core project team.

Goal:

The goal of this project is to further the development of educational materials that can then be used to raise rural consumer's awareness of HIE/HIT privacy and security issues.

Objectives:

i) Identify diverse rural consumer's HIE/HIT privacy and security education needs and solicit feedback on preferences in regards to dissemination of messages.

ii) Search for, customize, develop (where needed and feasible) and refine, educational materials for informing rural consumers on the areas identified as priority in HISPC II and through the local needs assessment.

iii) Develop a communication plan to disseminate the targeted messages on HIE privacy and security to rural consumers.

iv) Develop a plan to evaluate the impact of the HIT/HIE privacy and security education materials on knowledge and attitudes of rural consumers, and to document lessons learned.

v) Make rural education tool kit available to the consumer education and engagement collaborative common project and on the University of Kansas Center for Healthcare Informatics website.

Outcomes/Tools:

i) The project will pilot test and evaluate the outcomes including lessons learned from testing these educational materials with specific segments of the population.

ii) The final products from this project will become part of a tool kit for consumer education and engagement related to privacy and security of HIE/HIT.

iii) Summary report of analysis of consumer needs and preferences

iv) Useful data/ materials gathered during the process

v) Communication plan for dissemination of educational materials

vi) Evaluation plan for evaluating the outcomes of rural consumer education with results of pilot data included

vii) Summary report on lessons learned

viii) FAQs

ix) Glossary of relevant terms as defined in the common project

x) Website with educational tool kit related to the privacy and security issues available for other stakeholders in Kansas

Deliverables for Core Multi-state Collaborative Project: Development of a Glossary of Terms

As part of the core common project, Kansas will take the lead on developing a comprehensive and relevant glossary and document of key terms. Kansas is participating in the common project because we are developing materials that may be useful to a wide audience and also because we are interested in developing a national resource that consolidates the wealth of information and deliverables that exist.

The main tasks that Kansas expects to complete are:

- Search for existing glossaries and resources
- Remove redundancies and select pertinent terms to include
- Conduct a gap analysis

- Define new terms as needed
- Consult on the comprehensiveness, quality and relevance of terms
- Refine the key terms and glossary
- Organize terms in a usable form
- Solicit feedback
- Make terms available
- Provide project management and coordination via phone conferences for states to provide feedback and resources

For the common project, Kansas will work with individuals in the collaborative from Oregon, New York and Washington to accomplish the listed tasks. Kansas will:

- Research different organizations for materials on consumer education/engagement (e.g., AHIC, AHIMA, Regenstrief Institute, etc.)
- Contact and interview all HISPC states and territories to learn what consumer education/engagement tools they have used.
- Code the consumer education/engagement materials into appropriate technology architecture
- Create inventory matrix of consumer education/engagement resource
- Exchange information and findings.
- Share completed inventory of materials with larger Collaborative group for discussion and revisions.
- Conduct gap analysis, identifying what consumer education/engagement tools are currently missing, if any, and making suggestions for how to close that gap.

III. Impact Analysis

III.a. Project milestones and major findings.

February 2006 – Kansas' HISPC proposal was submitted to RTI. This proposal was developed by a group who would later become the core of the HISPC Steering Committee. Their collaboration signified a broad commitment to focus a portion of Kansas' HIT/HIE activities specifically on privacy and security policies and concerns.

July 2006 – Lieutenant Governor John Moore convened the first meeting of the HISPC Variations Working Group, establishing a close association between the activities of the Kansas HISPC project and the Kansas Health Care Cost Containment Commission.

October 2006 – Kansas attended a HISPC regional meeting in Kansas City. Also in attendance were delegations from Arkansas, Missouri, Oklahoma and Nebraska, as well as representatives of NGA, AHRQ, ONC, RTI and national thought leaders from Tennessee and North Carolina. This meeting was a milestone in Kansas HISPC collaboration with neighboring states.

November 2006 – The Kansas HISPC Variations Work Group (VWG) submitted its interim report. The VWG found that:

- Kansas' health care delivery system is as diverse as its geography. Large hospitals and health systems dominate in metropolitan areas, while a significantly larger number of critical access hospitals serve the state's rural areas. There are a few hospitals and large physician practices with sophisticated software capabilities, but the vast majority of providers do not have health information technology, most citing limited financial resources as a barrier. A study by the Kansas Foundation for Medical Care found that approximately 15-20% of physician offices have EHRs.
- There are also several health information exchanges in Kansas, including a Community Health Record pilot project in the Kansas Medicaid managed care program, a Kansas City based employer regional health information exchange (Healthe MidAmerica) and the Kansas City Regional Electronic Exchange.
- All stakeholders seem to have fully integrated HIPAA requirements into their procedures and rely on HIPAA to the exclusion of state law and regulation. Furthermore, the interpretations of HIPAA requirements vary greatly, so the implementation is uneven within stakeholder groups and among different stakeholders.
- State laws and regulations are antiquated and largely irrelevant to an electronic communications world. Yet the ignorance of or disregard for those laws and regulations may present traps and pitfalls for stakeholders. Those legal pitfalls do not appear to be on the stakeholders' radar screens of concerns as evidenced by the business practices identified during the VWG process which tend to focus on business process drivers rather than legal drivers.
- All stakeholders appear to have operational manuals covering HIE, but few representatives could cite specific policies without considerable effort. It appears that most stakeholders

approach HIE from the standpoint of "standard operating procedures" or practices, and not from recognized policies.

- Most stakeholders have adopted information technology in their practice setting operations and have adopted practices or policies to handle internal privacy and security issues arising from use of protected health information (PHI). However, most of these operations do not seem capable of readily allowing access to PHI from entities or individuals outside of their operations. This seems to be a result of blocking via operational practices and from the multiplicity of non-interoperable software systems.
- Future HIEs could be significantly burdened by each stakeholder's internal requirements/procedures for obtaining patient consent and release authorization.
- There is concern about the ability to obtain true "consumer" response to the HISPC efforts. One participant stated the need to develop a "trust attitude," to eliminate fragmentation and develop a truly patient-centered system.
- The Legal Work Group's (LWG's) preliminary assessment is that Kansas law and regulations are antiquated, largely failing to address issues of electronic HIE. For that reason, and because of the growing State-wide collaborative HIE efforts referenced earlier, the LWG anticipates its analysis will go well beyond the prescribed expectations of the HISPC exercise.
- One issue of considerable concern to some stakeholders, especially those bordering Missouri, is that HIE issues don't stop at political borders. Solutions to HIE barriers must ensure that "interoperability" is fully interstate.
- The LWG's independent analysis of the scenarios will go well beyond VWG identified business processes and will deal with broader legal concerns. As a result, the LWG will undoubtedly uncover areas of concern in state law and regulation that will need major overhaul to prepare the state for an HIE environment. The LWG's analysis will likely extend beyond the HISPC project and supplement the growing number of collaborative state-wide HIE efforts by suggesting needed revisions to state law and regulation that accommodate an electronic world.
- The VWG's and LWG's work is enhanced by the synergies of many members' participation in the range of other statewide HIE activities. The overlap of memberships among these efforts has enabled cross-pollination and enhanced the potential for a lasting impact from the HISPC) project.

Our experience to date suggests that irrespective of tangible results, considerable value will come to the Kansas healthcare delivery system from the HISPC project. The tasks of 1) determining relevant stakeholder groups, 2) identifying HIE leadership in each group, 3) coordinating two State-wide meetings in the Statehouse and convened by the Lt. Governor, and 4) developing among stakeholder groups, associations and individuals a shared focus on facilitating HIE, have created cohesion of disparate groups around HIE in Kansas. There is a developing a sense that 'we're all in this together'.

January 2007 – The Kansas HISPC Solutions Work Group (SWG) submitted its interim report. SWG subcommittees developed over 30 solution recommendations to address over 60 business practice variations across 9 domains. The SWG chose to organize the business variations and

proposed solutions in four foci: patients; business operations and policy; the law; and, regional interests. These focus areas were previously described in section I.c. of this report.

The SWG report concluded that one of the greatest benefits of HISPC will be the establishment of a strategic framework for conducting demonstration projects, for sharing lessons learned, and for producing one or more interoperable models for health information exchange. In this way, we hope to mitigate some risks of investment and promote growth of HIE best practices.

The challenges to adoption of HIE are strategic. Often, they are organized into four strategic dimensions: governance, finance, clinical practice and technology. Though privacy and security considerations cut across all of these dimensions, much of the attention of the HISPC project was focused on tactical concerns. In the VWG for example, representatives of various industries met to discuss such matters as the mechanism by which persons seeking access to electronic personal health information prove that they are whom they claim to be (Domain 1). The VWG, LWG and SWG each attempted to translate these operational concerns into strategic opportunities.

The stakeholder collaborations themselves are understood to be primary products of the HISPC process, and these collaborations are expected to outlive the project itself. The primary purpose of the Solutions Work Group report was to reinforce these two functions: translating operational issues into strategic opportunities, and providing recognizable landmarks to members of the Kansas collaboration as they plan to implement regional health information exchange solutions.

February 2007 – The Kansas HISPC Implementation Planning Work Group (IPWG) submitted its interim report. The IPWG report laid out six implementation goals:

1. Establish a statewide coordinating entity to facilitate HIE and continue the work of the HISPC team
2. Coordinate the interpretation of state and federal laws pertaining to the exchange of health information in Kansas
3. Identify healthcare informatics standards and best practices to improve the exchange of health information and monitor the evolution of national platforms.
4. Develop model policies, procedures, and guidelines for the exchange of health information
5. Educate healthcare entities and the public about the benefits and processes of health information exchange
6. Promote implementation of health information exchange

March 2007 – Kansas attended a national meeting of participating HISPC states and submitted its Final Reports. This meeting provided critical opportunities for sharing lessons learned and coordinating planning with other states. Among states who were at widely varying stages of HIE development, Kansas was able to find many commonalities.

May 2007 – AHRQ provided two months' bridge funding to enable states to prepare plans for continuation and coordination of implementation plans for the second half of 2007.

July 2007 – Kansas submitted a proposal for a 6-month contract extension to undertake foundational work based on recommendations of the 2007 Kansas HISPC Final Implementation Plan Report. Two projects were selected for their strategic importance and for their feasibility of rapid execution. Each project would sustain Kansas' momentum and would position us to

continue our efforts beyond the termination of the HISPC contract. The projects were those described in Section II of this document: 1) completing the first-phase of a long-term review of Kansas statutes and regulations related to health information privacy and security; and 2) establishment of a statewide HIT/HIE coordinating entity whose first project would be development of an educational toolkit.

September 2007 – The Kansas Health Information Exchange Commission delivered its proposal to the Office of the Governor for creation of a public/private HIE Coordinating Entity.

October 2007 – The Kansas catalog of statutes was completed.

November 2007 – Kansas attended a national meeting of HISPC and non-HISPC states for the purpose of developing joint proposals to receive funding as multi-state collaboratives in 2008.

III.b. HISPC project impact.

The most conspicuous outcome of the HISPC project in Kansas has been the engagement of a broad cross-section of stakeholders and policy makers in a discussion of statutory and regulatory reform. This project, as much as any of the state's HIT and HIE initiatives, raised the public's awareness of HIT/HIE and focused attention on the rights and responsibilities of those who share protected health information. HISPC's data collection tool, used for cataloging statutes related to HIE, is an important product on which Kansas and other states may continue to build.

The project produced a number of additional outputs and outcomes that support the first. HISPC's outreach to – and collaboration with – diverse stakeholder interests was not unique in Kansas, but was clearly valuable and clearly reinforced similar efforts by the Health Care Cost Containment Commission, the Kansas Hospital Association and others. The collaborations fostered by HISPC are expected to outlive the project itself. Already, they have fostered new coalitions of organizations who have banded together to produce proposals to obtain funding for HIT/HIE related projects. Among these are two proposals to the Federal Communications Commission and one to the Kansas Bioscience Authority.

During the term of the HISPC project, Governor Sebelius established the Health Information Exchange Commission (HIEC), to which she appointed two members of the HISPC Steering Committee as Co-Chairs. The HIEC prepared for the Governor's consideration a proposal for a new public-private partnership to coordinate HIE development in the state. If authorized, one of the first programs to be undertaken by that partnership could be an HIE privacy and security curriculum for rural health care consumers. That curriculum is being developed in Phase II of the HISPC project and will be further address through the Consumer Education and Engagement Collaborative.

Many of the staff and leadership of the Kansas HISPC project believe that one of the most valuable benefits of the project has been the opportunity to meet with and learn from our counterparts in other parts of the country. The multi-state collaborations in which we now are participating should enable Kansas to develop more effective policy and institutions at the local, regional and national levels.

III.b.1 HISPC project impact on business variation in privacy and security practices.

In Kansas, HISPC's impact on variation in business policies and practices has not been obvious to the general population, thus far. However, changing business practices and policies is not something that happens quickly. The strategies and activities surrounding the HISPC project laid the ground work for change which hopefully will be realized as implementation plans are rolled out. It is also important to note that reduction of business variation was not one of the areas selected by Kansas' HISPC Steering Committee for short term intervention. This is not to say that business policies and procedures have remained static, rather it is that the change is not noticeable. As we noted earlier, political and technological forces – particularly at the national level – have begun to align and accelerate towards a clearer set of opportunities and needs that will influence the future change in business practices.

In addition, both of Kansas' privacy and security initiatives for 2008 are expected to further prepare the landscape for future reduction of variation. We expect better informed consumers of health care services to express their privacy and security interests forcefully in the marketplace and in the halls of government. Our statewide coordinating entity, when established, will intervene directly by setting privacy and security standards for health information exchanges that seek to become established in the state. And, the HISPC legal working group is preparing the ground for statutory and regulatory reform that should clarify the rights and responsibilities of all parties to HIE. Clearly, these initiatives coupled with the national HIE agenda will result in noticeable change.

III.b.2 HISPC project impact on leadership and governance.

The HIEC proposal for a statewide HIE coordinating entity remains under consideration in the Office of the Governor. As noted earlier, the HIEC and the HISPC Steering Committee share many members, so HISPC regards the HIEC proposal as its own.

The HIEC proposal itself drew heavily from the work of the Kansas HIT/HIE Policy Initiative. That body established four workgroups: governance, finance, technology, and clinical issues. Those workgroups produced detailed reports, describing perceived strengths and weaknesses of alternative models for organizational structure, governance, leadership, sustainable finances, and technical and clinical interactions between the public and private sectors.

Kansas' InformationLinks report extended our understanding of other states' approaches to such interactions, particularly as related to public health, and made specific recommendations, among which was the need for an early focus on control of the Master Patient Index and on clarifying patient authorization and consent at the nexus of private and public health care.

Kansas' public debate about leadership and governance is just getting started, but the HISPC work groups, HIE Commission and other projects and collaborations start us off at a high standard. Their reports have in many senses defined the terms of debate. Their deliberations and their histories of collegial interaction have defined the processes by which we intend to arrive at effective solutions to our current challenges and promote the continuing evolution of HIE organizations, practices and technologies to improve the health of Kansans.

III.b.3. HISPC project impact on stakeholder knowledge and education issues.

Typical of other HISPC states, Kansas wrestled with the problem of how to engage consumers' voices in the project. In the earliest phase, when the project focused on analysis of 18 scenarios, the work groups concluded that most consumers would have been ill-prepared to participate in the deliberations. Kansas' Variations Work Group (VWG) report noted that, "The HISPC forms are too complex and cumbersome to be utilized by consumers unrelated to the process, and most scenarios don't pertain to issues that patient / consumers regularly deal with." The VWG strove to include consumer voices through its engagement of advocacy groups and government departments such as the AFL-CIO, the Kansas Health Consumer Organization, the Kansas Association for the Medically Underserved, the Kansas Department of Social and Rehabilitative Services, and the Kansas Office of Local and Rural Health.

The implementation phase of the HISPC project in the second half of 2007 has explicitly sought to prepare consumers to participate more fully in this process by developing a HIT/HIE privacy and security curriculum for them. The plan is for this curriculum to be delivered to the public by the HIE coordinating entity to be established in 2008.

The involvement of hospital- and university-based Area Health Education Centers (AHECs) in developing and delivering the consumer curriculum prepares us well to develop curricula for providers and other constituencies in future months.

III.b.4. HISPC project impact on funding and stability of HIE/HIT efforts

The funding and stability of HIT/HIE efforts in Kansas rides in large measure on the outcome of current proposals for the HIE Coordinating Entity.

III.b.5. HISPC project impact on other areas

The project has fostered a sharpened focus on the work of harmonizing laws, educating consumers, and prioritizing HIE issues and challenges which need to be addressed in Kansas. HISPC has helped consolidate previously fragmented discussions and has engaged new stakeholders in these discussions. It has probably accelerated the work of other HIT/HIE projects.

Because so many stakeholders and others were involved in HISPC, it has brought the electronic exchange of health information and the core issues of privacy, security and confidentiality to the attention of the public at large. More individuals are asking questions about what this means for them.

The synergy of HISPC with other projects has allowed us to leverage resources to bring privacy and security issues to the forefront. The project helped leverage what has been happening in the state in favor of HIE and the Commission's efforts to accelerate work on HIT/HIE in general. It also probably increased attention, funding and long-term planning activities surrounding HIT.

HISPC produced informal discussions between Kansas, Missouri and Nebraska. Planning for the 2008 collaborative enabled us to see where Kansas is in relation to other states and to learn from others' successes and setbacks.

III.c. Unanticipated outcomes

None.

IV. Future Vision

IV.a. Within the state

As noted earlier, the funding and stability of HIT/HIE efforts in Kansas rides in some measure on the outcome of current proposals for the HIE Coordinating Entity. Regardless of the immediate outcome, it is our belief that a statewide resource center for coordination, consultation, education and research will emerge in some form.

Also, Kansas' commitment to its ongoing role in two HISPC multi-state collaboratives – Harmonizing Laws and Consumer Education and Outreach – is expected to yield immediate and consequential outcomes within the state.

And, these are not the only continuing HIT/HIE initiatives in Kansas. Our fledgling RHIOs – based on such diverse models as employer-based EHRs, referrals among safety net providers on either side of the state line, and expedited payment systems – continue to seek ways to adapt to evolving demands and opportunities. The Kansas Health Policy Authority has proposed creation of statewide CHRs for beneficiaries of Medicaid and SCHIP and subscribers in the State Employees Health Plan. And, a U.S. senator and congressman from Kansas have each introduced federal legislation to establish patient-owned Independent Health Record Trusts.

The pace at which we approach our HIE future depends also on outside factors. Numerous health and health care issues vie for the public's and policy makers' attentions. These include Medicaid reform, the uninsured, health literacy, tobacco use and the epidemic of obesity. We believe that ensuring private and secure exchange of health information has a significant role to play in the solutions to all of these challenges.

IV.a.1. Specific challenges to private and secure interoperability identified in Phase I still needing resolution.

Six implementation strategies were indentified in Kansas' HISPC Implementation Planning report. In the second half of 2007, three of these were selected for immediate attention. The other three were:

3. Identify healthcare informatics standards and best practices to improve the exchange of health information and monitor the evolution of national platforms.

4. Develop model policies, procedures, and guidelines for the exchange of health information.

6. Promote implementation of health information exchange

In addition, Kansas' Solutions report identified a number of areas that remain challenges for 2008 and beyond, such as establishing standards for patient consent.

IV.a.2. Plan and/or commitment within the state to resolve these issues.

Much of the work of carrying the momentum and achieving the remaining objectives of the HISPC project will depend on the mandate and the resources provided for the proposed HIE Coordinating Entity.

IV.b. Multi-state Initiatives

We believe that the processes and methodologies for reviewing and revising laws that we develop for the Kansas HISPC project will be adoptable by many other states. We hope to coordinate our statutory and regulatory review efforts with those of the State of Missouri, in particular, which shares jurisdiction over parts of the Kansas City metropolitan area. We are pleased to learn of Missouri's very recent entry into the HISPC multi-state collaborative for harmonizing state laws.

We also expect to share our work with the National Conference of Commissioners on Uniform State Laws (NCCUSL) Study Committee on Health Information Interoperability, one of whose members is a Kansas State Representative.

The opportunity to continue this work and see these efforts through to adoption of new legislation is essential to achieving nationwide and state-specific HIPAA harmonization and HIE enabling legislation.

IV.b.1. Interactions among states that have been of value.

Kansas is a bit further along with its planning for statutory reform than some other states in the Harmonizing Laws collaborative. However, some states outside the Harmonizing Laws collaborative (because they have chosen to participate in other collaboratives) have already passed HIE privacy and security legislation. We look to these and to our collaborative partners for lessons learned and for cooperation in what will inevitably be multi-state solutions.

Similarly, we have learned that some states in the Consumer Education and Outreach collaborative already have produced sophisticated educational media related to HIE privacy and security. We hope to incorporate their work products into our own education and outreach efforts.

IV.b.2. Intended/future outcomes of Collaborative work

See above.

V. Conclusion

The health sector comprises nearly one-sixth of the gross domestic product of the United States. Health information is the vocabulary with which we describe this vast activity, and health information exchange is the process by which all parties to the enterprise communicate with one another. Recent advances in electronic communications have created sea-changes – both quantitatively and qualitatively – in the nature of those communications. Only recently have we begun to reinvent policies and practices in response to these new capabilities and challenges for health information exchange.

The good news is that ordinary citizens are engaged as never before in managing their own information and are thereby better empowered to manage their own health. More good news arrives in the form of early evidence that health information technology, properly implemented – holds promise for enabling us to manage the cost, quality and safety of health care services.

These opportunities are counterbalanced by massive short term obstacles. Adopting currently available health information technologies requires businesses to comprehensively review and revise their policies and practices. Economic incentives are misaligned. Understanding of the laws is weak. The laws themselves are out of date.

Over the past four years, the Governor of Kansas has created a series of opportunities for broad coalitions of citizens to convene and to begin forging solutions to those parts of the problems that can be addressed at local, state and regional levels. HISPC – the Health Information Security and Privacy Collaboration – has been an integral part of this work. HISPC stakeholders produced breakthrough studies of barriers and solutions to private and secure exchange of health information in Kansas. The project has also served to bind together and carry forward the efforts of other Kansas initiatives.

For the second half of 2007, the HISPC Steering Committee chose three implementation strategies on which to focus:

- Establish a statewide coordinating entity to facilitate HIE and continue the work of the HISPC team.
- Coordinate the interpretation of state and federal laws pertaining to the exchange of health information in Kansas.
- Educate healthcare entities and the public about the benefits and processes of health information exchange.

These ambitious plans touched many areas of the public and private sectors and were somewhat altered through that process. The proposal for a statewide coordinating entity went forward under the auspices of the Governor's HIE Commission, a body that shares many members with the HISPC project. We await the Governor's leadership in securing future resources for that effort. Kansas HISPC's analysis of state and federal laws – the result of an extraordinary level of volunteered professional effort – was enormously successful and may serve as a model for other states. The HISPC Legal Work Group is concluding its work for 2007, drafting the first statutory language that it will propose based on its findings. Kansas' Education Work Group, in the process of developing an HIE privacy and security curriculum for rural health care consumers, encountered another state organization engaged in related activity (KHIMA). Choosing to

coordinate rather than duplicate efforts led to a minor reallocation of resources and extension of their timeline. We have negotiated with AHIMA to adapt and expand their foundational curriculum and to collaborate with them through this process.

Looking forward to 2008 and beyond, Kansas HISPC teams are enthusiastically participating in two multi-state collaborations: harmonizing state laws, and consumer education and engagement. For obvious reasons, we expect these efforts to further leverage the work that we have already done. We view the continuation of this work as critical for carrying our earlier efforts to the "tipping point" of public commitment to a health information rich future.